Childhood Cancer in Kentucky

2011-2020

Prepared by:
Chaney Blu
Bin Huang, DrPH
Eric B. Durbin, DrPH, MS
Ivelina Todorova
Stephanie Barber

Contact Information:
Kentucky Cancer Registry
Markey Cancer Center
University of Kentucky
2365 Harrodsburg Road, Suite A230
Lexington, KY 40504-3381
Website: https://www.kcr.uky.edu
Telephone: 859-218-6227
Facsimile: 859-257-4177

Suggested citation:
Kentucky Cancer Registry Childhood Cancer Incidence 2011-2020. Lexington, KY: University of Kentucky, Markey Cancer Control Program; 2024. Based on data released November 2022.

Version 006-2024-01

Acknowledgements

The population-based childhood cancer incidence data presented in this report was made possible by the Kentucky General Assembly that passed Senate Bill 41 in April 1990. This legislation formally established the Kentucky Cancer Registry (KCR) as the official cancer surveillance program for the Commonwealth of Kentucky and mandated reporting of all cancer cases to the KCR beginning on January 1, 1991. Kentucky Revised Statute (KRS) 214.556 continues to require reporting from all health care facilities that either diagnose or treat cancer patients. Facilities include acute care hospitals, freestanding treatment centers, non-hospital (private) pathology laboratories, physician offices and genomic testing facilities. KCR gratefully acknowledges the full and active participation of facilities throughout Kentucky and a number of facilities outside of Kentucky. Their efforts are essential to complete, timely, and accurate reporting of all childhood cases occurring in Kentucky.

Beginning in 1994, the KCR was awarded funding from the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries (NPCR). This additional funding allows KCR to maintain a formal quality assurance program, implement complete death clearance follow back, and ensure that all cases of cancer are systematically reported by Kentucky's non-hospital facilities. In 2001, the KCR was awarded critical support from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program, to further improve patient follow-up information and support expanded quality assurance activities. KCR has been successful in re-competing and sustaining all of these funding sources since the initial awards. KCR was awarded contract renewals to continue through 2028 as an NPCR registry and as a SEER Program Registry. KCR has recently received two competitive awards to participate in the development of the National Childhood Cancer Registry, an initiative led by the National Cancer Institute.

Finally, special recognition is given to the professional staff of the KCR. Informatics staff develop, maintain and support software, databases and technical infrastructures used throughout Kentucky. Operations staff have developed training programs and provide ongoing support to all of the reporting facilities throughout the state. Biostatistics and epidemiology faculty provide support for cancer prevention and control activities and research with KCR data. All of these individuals are highly engaged in cancer surveillance activities and standards development at the national and international levels. KCR could not be successful without the consistent contributions of these talented and dedicated individuals.

This project has been funded in whole or in part with Federal funds from the Centers for Disease Control and Prevention and the National Cancer Institute, National Institutes of Health, Department of Health and Human Services, under Cooperative Agreement No. 5NU58DP006313 (NPCR) and Contract No. HHSN261201800013I (SEER).

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Introduction

This report of population-based childhood cancer incidence for the Commonwealth of Kentucky represents the most accurate data available at the time of publication. This report includes complete data through the 2020 diagnosis year that are available from KCR and also available nationally. KCR collects uniform, high quality data on approximately 229 new primary cases of childhood cancer occurring in Kentucky residents each year. Childhood cancer is defined as all newly diagnosed malignant invasive neoplasms occurring among all children living in Kentucky under the age of 20. This report provides detailed information about childhood cancer in Kentucky for the most recent ten year period of complete, population-based data collected and validated by KCR. Information includes case counts by sex, age and site groups. Site groupings by body site and histologic type are defined by the International Classification of Childhood Cancer (ICCC) [1] and permit comparisons of incidence rates within and outside of Kentucky. This report also provides information about age-adjusted childhood cancer incidence rates, defined as the number of new cases diagnosed, divided by the numbers of persons at risk during the calendar year(s). Age-adjustment calculates the rates according to a standard age distribution. This is necessary to allow comparisons between regions with different age distributions. All rates in this report are per 1,000,000 (million) individuals at risk for the given cancer. It should be noted that rates per million differ from reports that include adult cancers which are typically reported per 100,000. Because of the relatively small numbers of cases, rates for small geographic regions can be deemed unstable, meaning too few cases to calculate a reliable rate. Unstable rates tend to exhibit large fluctuations with the increase or decrease of even a single case from year to year and can therefore be easily misinterpreted as representing a greatly increased or diminished risk of diagnosis. As a result, unstable rates with the number of cases less than 15 are not included in this report.

This report provides information that permits regional comparisons among Kentucky's Area Development Districts (ADD), Appalachian/non-Appalachian counties, and Urban/Rural counties within the state. ADD maps display four distinct colors. Each color represents a quartile, or one-fourth of the range of incidence rates from lowest in yellow, to highest in red. Information is also provided to permit comparisons of age-adjusted rates in the U.S. with Kentucky and Appalachian Kentucky.

Overview

Childhood cancer is relatively rare, with less than 1% (2,283 / 273,254) of all cancers diagnosed in Kentucky occurring among children under the age of 20 during the years 2011-2020. However, a cancer diagnosis is severely burdensome for these children and their families. In addition to the side effects from surgeries, chemotherapeutics and/or radiation on developing body systems, there are often lifelong economic and social costs for affected families. Over 83% of children diagnosed with cancer survive at least 5 years [2], yet cancer remains the leading cause of disease-related death among U.S. children. Brain and central nervous system (CNS) tumors have recently overtaken leukemia as the leading cause of cancer-related death among children [3].

From 2011 through 2020, the most recent ten years of complete data presented in this report, 2,283 children in Kentucky were diagnosed. Cancer occurred more frequently among males (54%) than females (46%).

The frequency of cancer diagnoses varied by age, with cancers occurring most frequently among children ages 0-4, followed by children ages 15-19, 10-14 and 5-9, respectively. Males were diagnosed with more cancers across all site groups except for epithelial tumors & melanoma and renal tumors. Among all Kentucky children, leukemia occurred most frequently (22%), followed by brain and CNS tumors (20%), lymphoma (16%), and epithelial tumors and melanoma (13%). These top four site groups represent 72% of all childhood cancer diagnoses during this time period.

The frequency of diagnoses by cancer site group also varied by age group. Of note, a greater proportion of hepatic tumors occurred among children ages 0-4, while more leukemia cases occurred among children ages 0-4 and 5-9. Children ages 5-9 also experienced the greatest proportion of brain and CNS tumors. Lymphoma, epithelial tumors & melanoma, and germ cell & gonadal tumors increased proportionally with age, while sympathetic nervous system tumors, renal tumors, and retinoblastoma decreased proportionally with age. The greatest proportion of soft tissue sarcomas and bone tumors occurred among children ages 10-14. The age-adjusted incidence rates of childhood cancer have increased by over 1.78% annually among both males and females over years 2011-2019. Year 2020 was excluded from the trend analysis due to the COVID pandemic, which caused a big drop of the number of new cases in year 2020. Increasing rates of childhood cancer have been observed throughout the U.S. [2]

Regional comparisons within Kentucky indicate that the highest rates tend to occur in the eastern regions of the state with Appalachian Kentucky experiencing a higher rate than non-Appalachian Kentucky. According to the most recent national data available (2011-2020), Kentucky's age-adjusted childhood cancer incidence rate for all cancer sites is approximately 4.3% higher than in the U.S. [4]. Rates in Kentucky and Appalachian Kentucky are higher than in the U.S. for both males and females. Comparisons to U.S. rates by site group indicate that Kentucky children and/or Kentucky Appalachian children have higher rates across all major site groups except for soft tissue sarcomas and renal tumors. Rates of leukemia are lower than the U.S. for all Kentucky children but higher among Appalachian children. Of particular concern, rates of brain and CNS tumors and epithelial tumors and melanoma are significantly higher in Kentucky compared to the U.S. and also significantly higher among Kentucky Appalachian children for brain and CNS tumors, epithelial tumors and melanoma, and retinoblastoma. Kentucky is ranked with the 6th highest rate for all invasive cancer sites combined. However, Kentucky has the highest rate of hepatic tumors, 3rd highest rate of brain and CNS tumors, 3rd highest rate of retinoblastoma, and 5th highest rate of epithelial tumors and melanoma.

1. Steliarova-Foucher E, Colombet M, Ries LAG, Hesseling P, Moreno F, Shin HY, Stiller CA, editors (2017). International Incidence of Childhood Cancer, Volume III (electronic version). Lyon, France: International Agency for Research on Cancer. Available from: http://iicc.iarc.fr/results/.

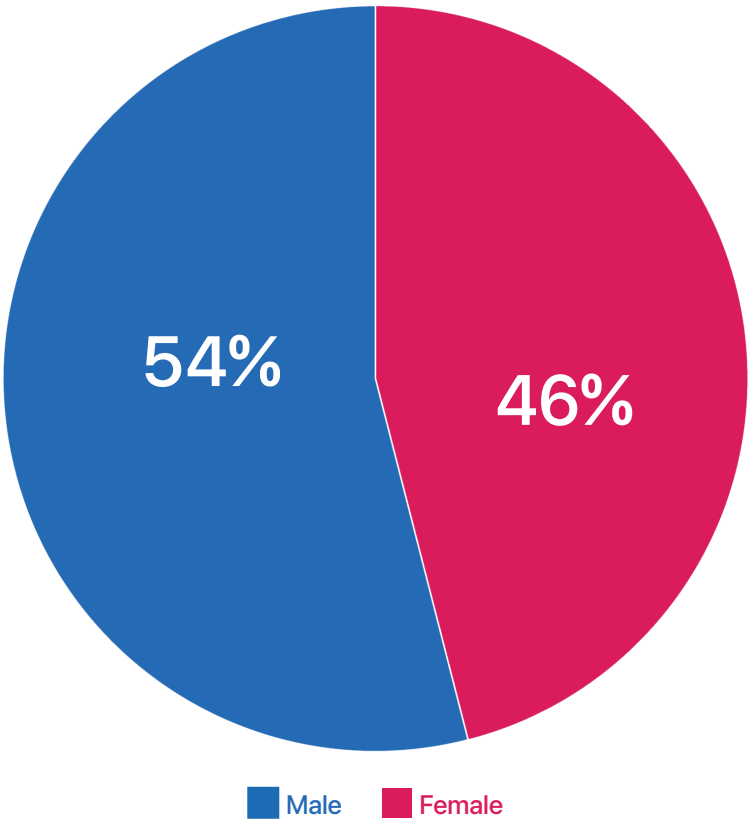
2. Noone AM, Howlader N, Krapcho M, Miller D, Brest A, Yu M, Ruhl J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2015, National Cancer Institute. Bethesda, MD, https://seer.cancer.gov/csr/1975_2015/, based on November 2017 SEER data submission, posted to the SEER web site, April 2018.

3. Curtin SC, Minino AM, Anderson RN. Declines in cancer death rates among children and adolescents in the United States, 1999-2014. National Center for Health Statistics Data Brief 2016; 257:1-8.

4. United States Cancer Statistics: 1999 - 2020 Incidence, WONDER Online Database. United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2023. Accessed at http://wonder.cdc.gov/cancer-v2020.html.

CHILDHOOD CANCER INCIDENCE IN KENTUCKY
ALL SITES, 2011-2020

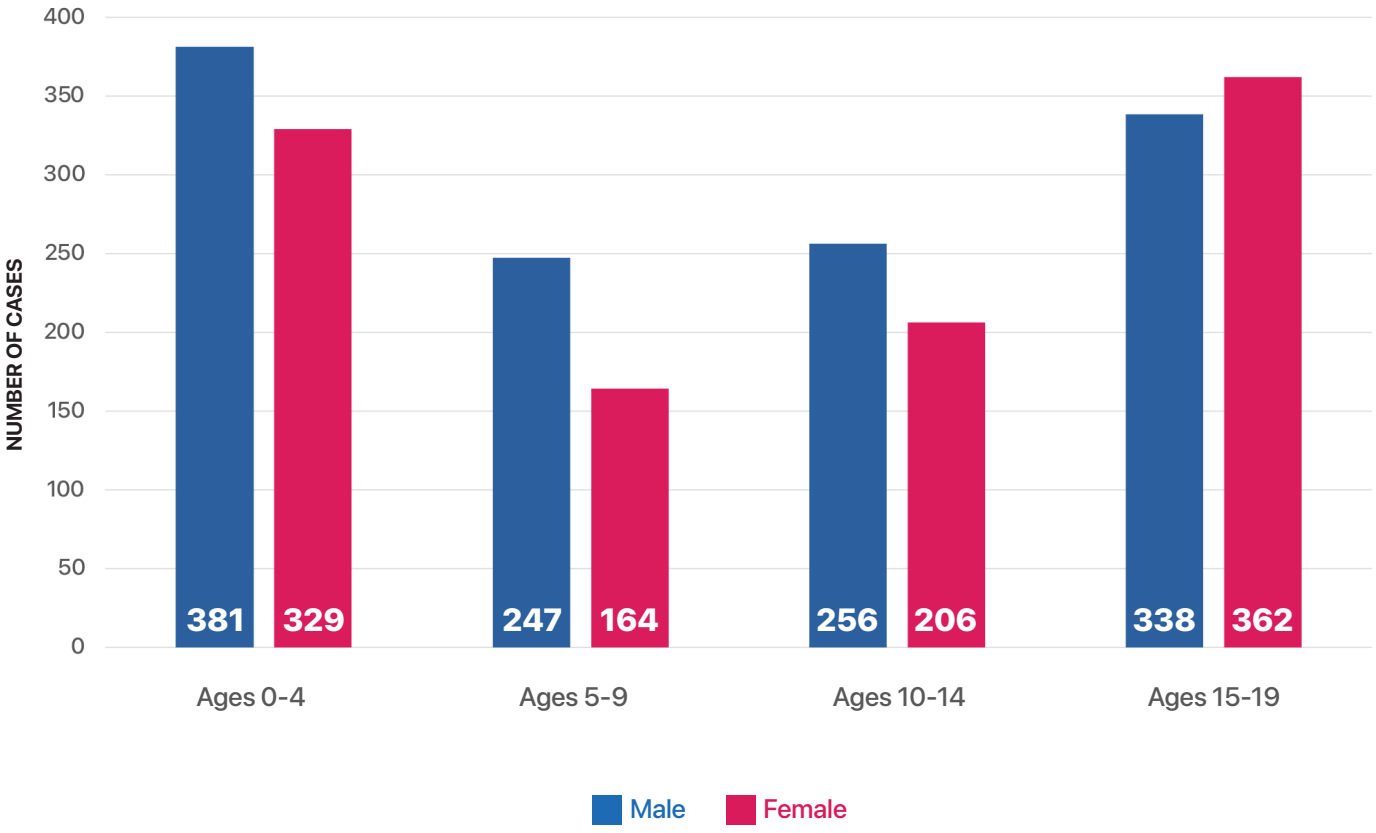
PROPORTION OF CASES BY SEX



Sex	Number of Cases (Percent)
Male	1,222 (54%)
Female	1,061 (46%)
Total	**2,283**

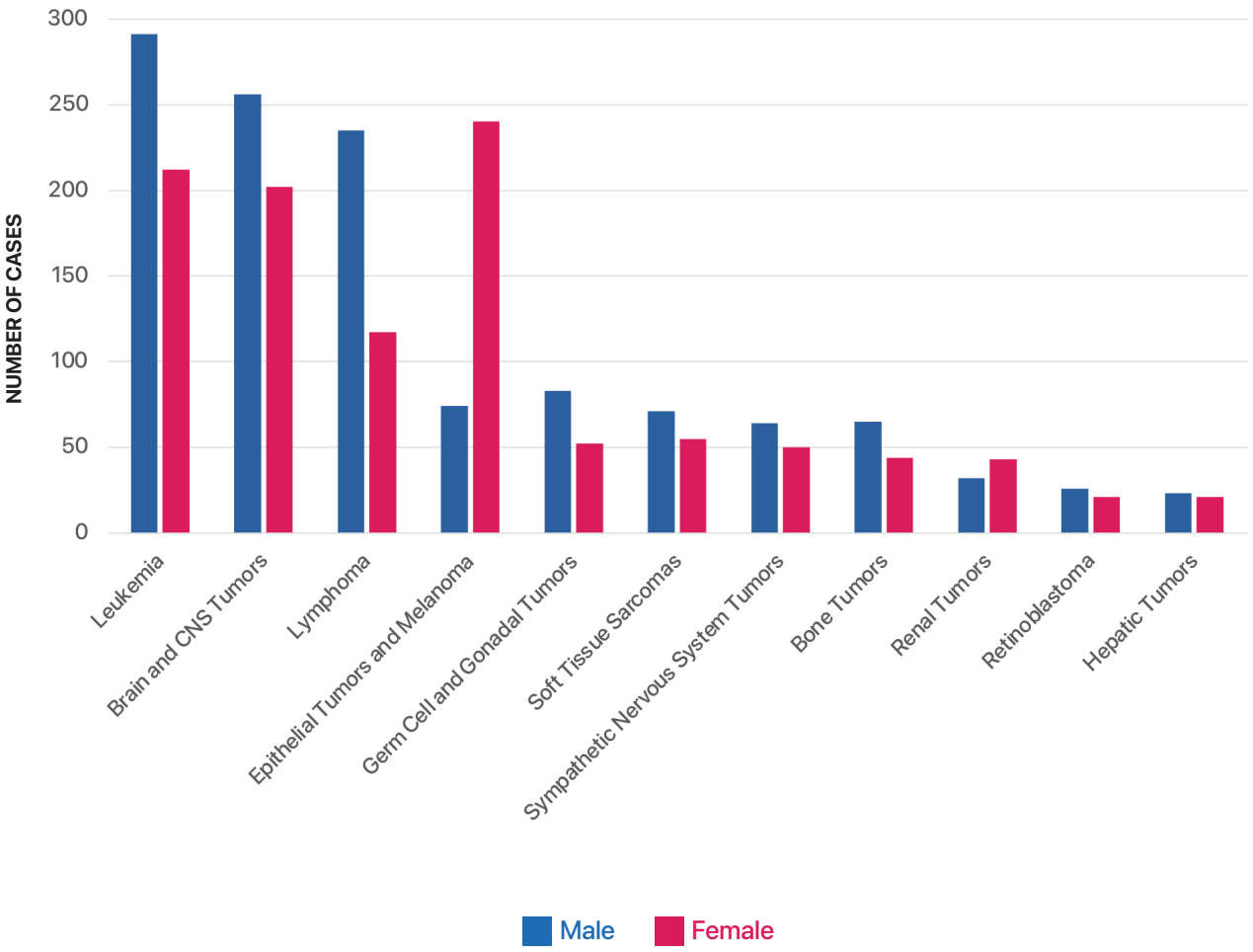
CHILDHOOD CANCER INCIDENCE IN KENTUCKY
ALL SITES, 2011-2020

CASES BY SEX AND AGE AT DIAGNOSIS



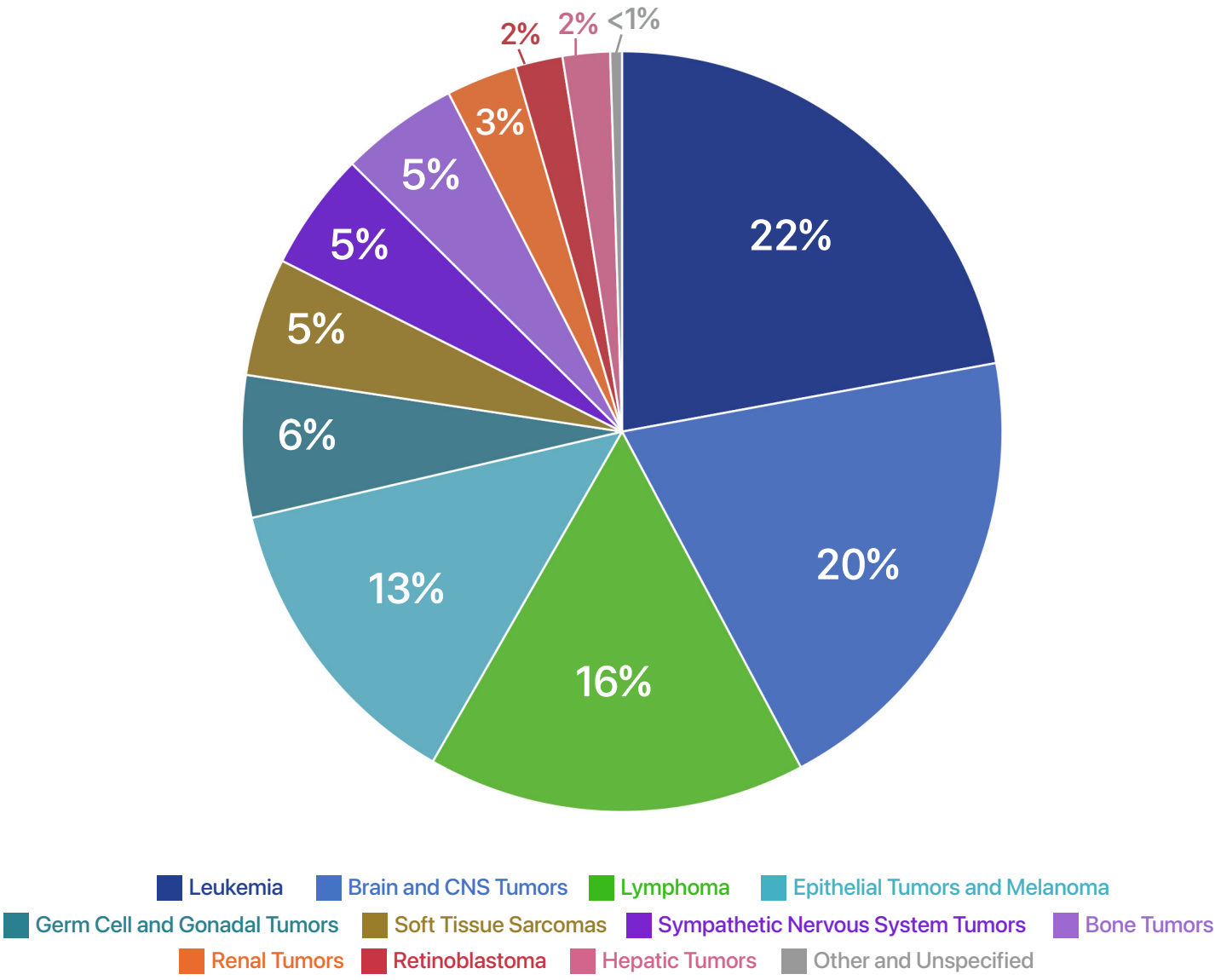
CHILDHOOD CANCER INCIDENCE IN KENTUCKY BY SITE GROUP, 2011-2020

CASES BY SITE GROUP AND SEX



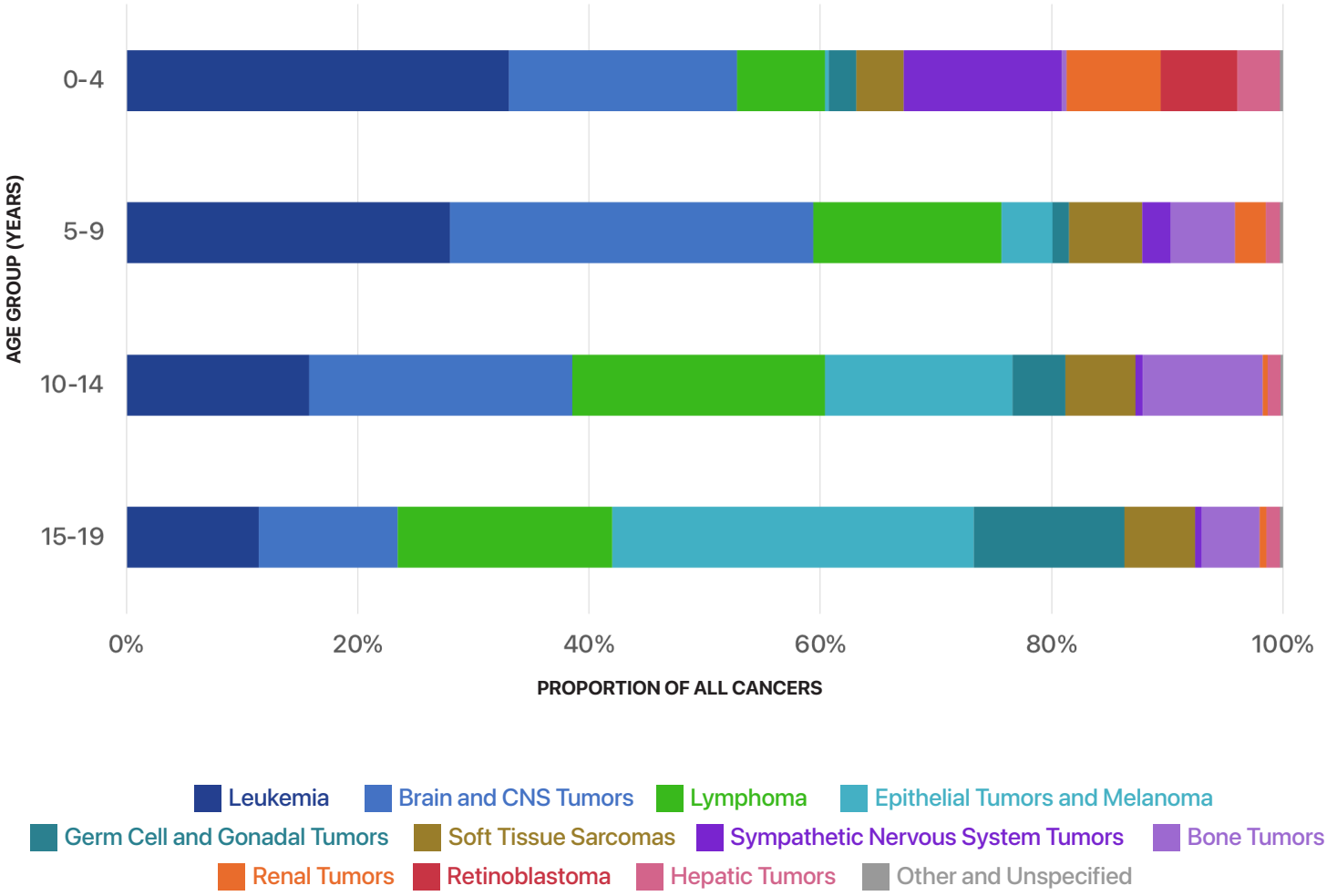
CHILDHOOD CANCER INCIDENCE IN KENTUCKY BY SITE GROUP, 2011-2020

PROPORTION OF CASES BY SITE GROUP



CHILDHOOD CANCER INCIDENCE IN KENTUCKY BY SITE GROUP, 2011-2020

PROPORTION OF CASES BY SITE GROUP AND AGE GROUP



CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY BY SITE GROUP, 2011-2020

SITE GROUP	BOTH SEXES		MALE		FEMALE	
	Cases	Age-Adjusted Rate	Cases	Age-Adjusted Rate	Cases	Age-Adjusted Rate
All Sites	2,283	201.8	1,222	210.9	1,061	192.4
Leukemia	503	44.4	291	50.2	212	38.4
Brain and CNS Tumors	458	40.6	256	44.3	202	36.7
Lymphoma	352	31.2	235	40.7	117	21.2
Epithelial Tumors and Melanoma	314	27.7	74	12.7	240	43.5
Germ Cell and Gonadal Tumors	135	11.9	83	14.2	52	9.4
Soft Tissue Sarcomas	126	11.2	71	12.3	55	10.0
Sympathetic Nervous System Tumors	114	10.0	64	11.0	50	9.0
Bone Tumors	109	9.7	65	11.3	44	8.0
Renal Tumors	75	6.6	32	5.5	43	7.8
Retinoblastoma	47	4.1	26	4.4	21	3.8
Hepatic Tumors	44	3.9	23	4.0	21	3.8

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

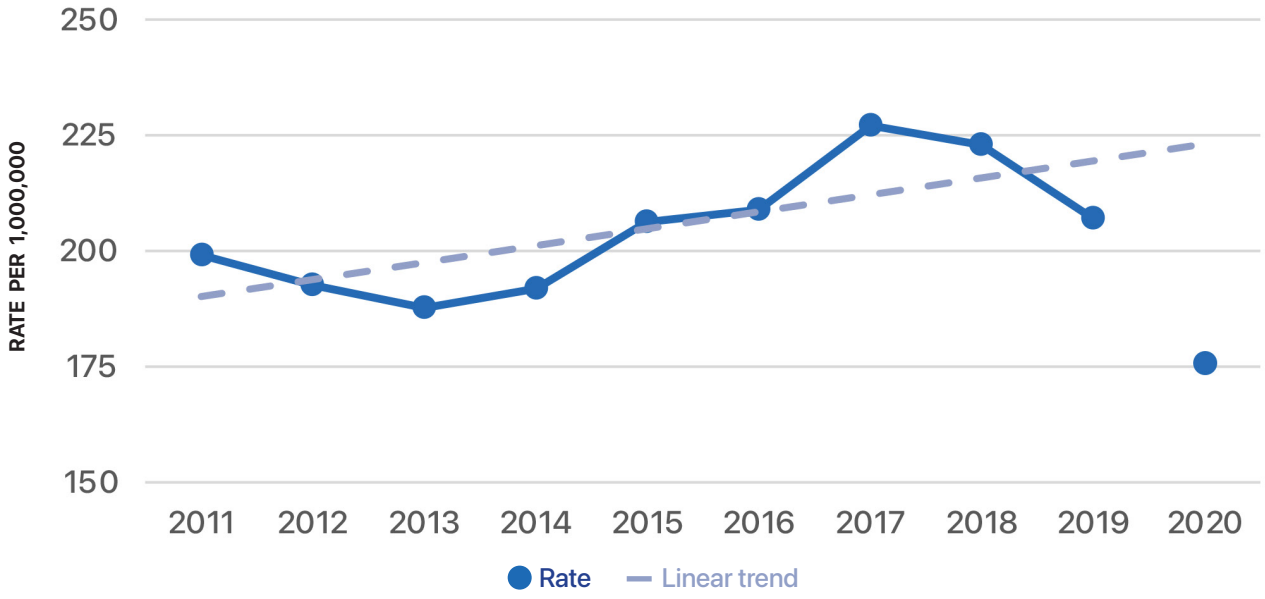
CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2011-2020

BOTH SEXES

Year	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2011-2020
Population at Risk	1,141,108	1,134,739	1,133,156	1,128,369	1,126,551	1,125,655	1,126,004	1,124,283	1,120,714	1,115,531	11,276,110
Total Cases	228	219	213	217	233	236	257	251	233	196	2,283
Crude Rate	199.8	193.0	188.0	192.3	206.8	209.7	228.2	223.2	207.9	175.7	202.5
Age-Adjusted Rate	199.1	192.5	187.6	191.9	206.1	208.8	227.0	222.8	207.0	175.5	201.8
95% CI Lower	174.1	167.9	163.2	167.2	180.5	183.1	200.1	196.1	181.3	151.8	193.6
95% CI Upper	226.7	219.8	214.6	219.2	234.3	237.3	256.5	252.1	235.4	201.9	210.3

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

AGE-ADJUSTED INCIDENCE RATE TREND



The age adjusted rate in 2020 was excluded from the trend analysis due to COVID and the sharp drop of the rate in year 2020. For the period in years 2011-2019, incidence rates have increased significantly, with a 1.78% annual percent change (APC). The trend line shows in the figure is based on a linear regression over 2011-2019. The APC is calculated using the JointPoint Trend Analysis software package developed by NCI SEER (https://surveillance.cancer.gov/joinpoint).

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2011-2020

MALE

Year	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2011-2020
Population at Risk	584,886	581,681	581,084	578,402	577,424	576,668	576,967	576,291	574,761	571,810	5,779,974
Total Cases	128	125	124	112	131	119	134	136	113	100	1,222
Crude Rate	218.8	214.9	213.4	193.6	226.9	206.4	232.2	236.0	196.6	174.9	211.4
Age-Adjusted Rate	218.4	214.3	212.9	193.2	225.9	205.6	231.1	235.8	195.9	174.7	210.9
95% CI Lower	182.2	178.4	177.1	159.1	188.9	170.3	193.7	197.8	161.5	142.1	199.2
95% CI Upper	259.7	255.3	253.9	232.5	268.1	246.1	273.8	278.9	235.6	212.5	223.0

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY
ALL SITES, 2011-2020

FEMALE

Year	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2011-2020
Population at Risk	556,222	553,058	552,072	549,967	549,127	548,987	549,037	547,992	545,953	543,721	5,496,136
Total Cases	100	94	89	105	102	117	123	115	120	96	1,061
Crude Rate	179.8	170.0	161.2	190.9	185.8	213.1	224.0	209.9	219.8	176.6	193.0
Age-Adjusted Rate	178.8	169.7	161.0	190.5	185.1	212.3	222.7	208.9	218.6	176.3	192.4
95% CI Lower	145.5	137.1	129.3	155.8	151.0	175.6	185.1	172.5	181.3	142.8	181.0
95% CI Upper	217.5	207.6	198.1	230.6	224.8	254.4	265.7	250.8	261.5	215.3	204.3

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY
ALL SITES, 2011-2020

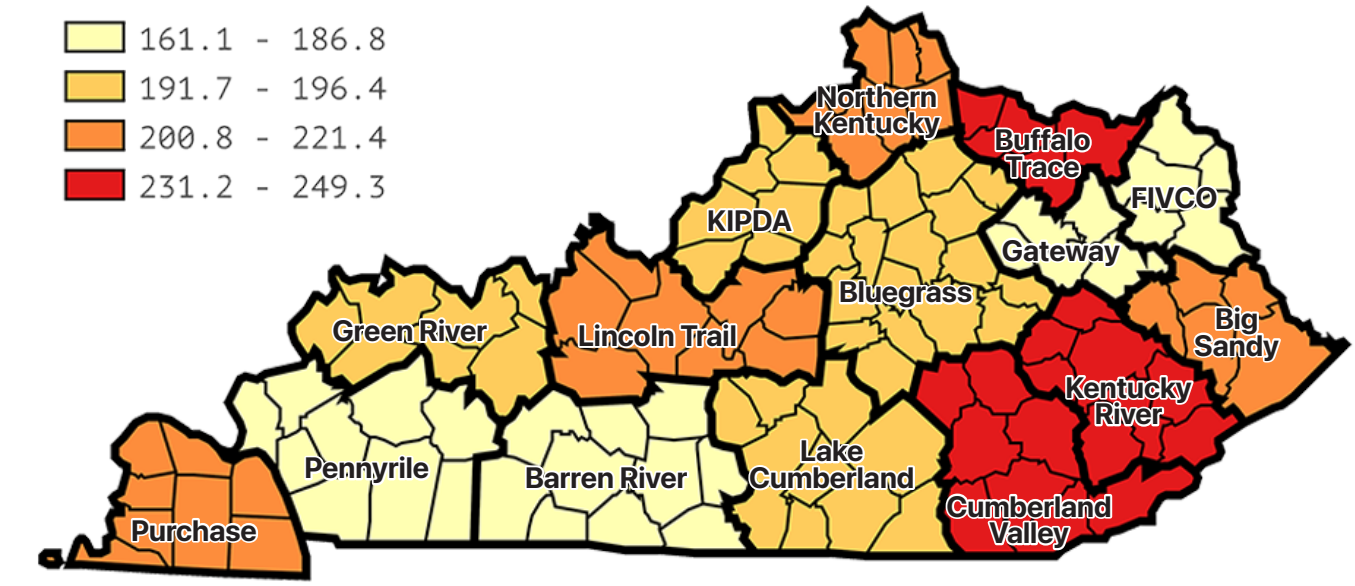
BY AREA DEVELOPMENT DISTRICT

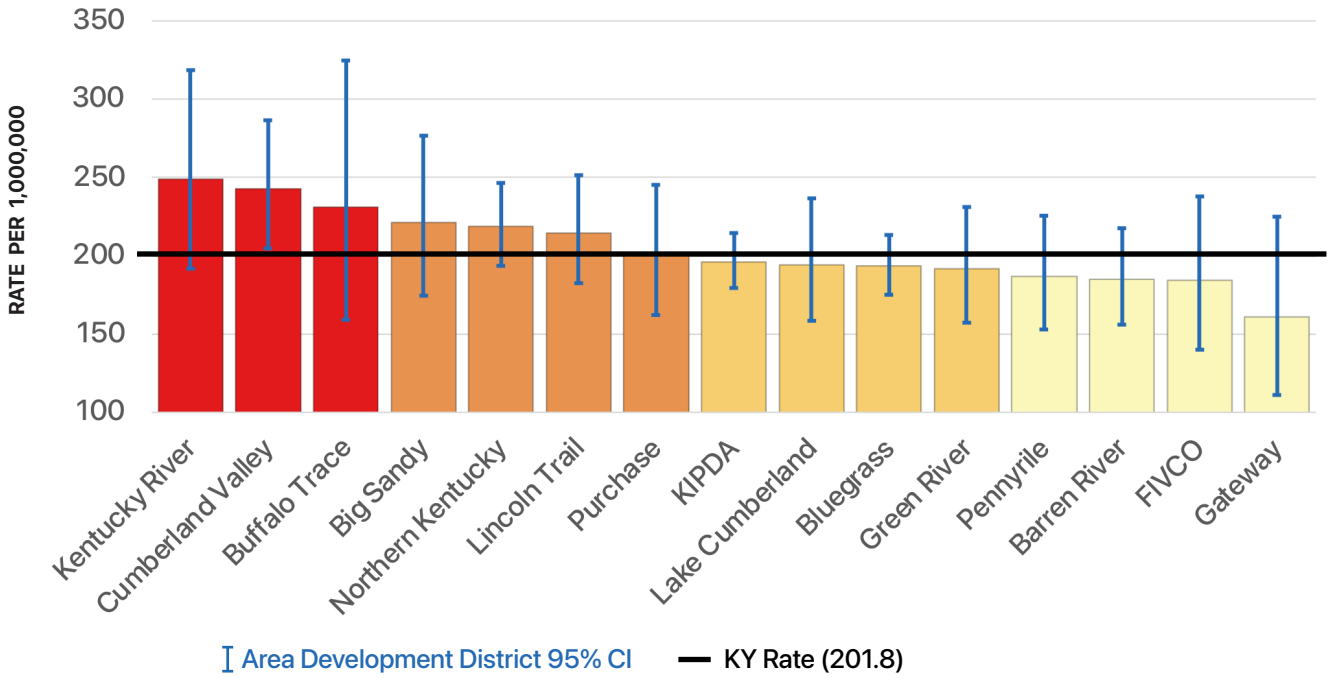
Area Development District	Population at Risk	Cases	Crude Rate	Age-Adjusted Rate	95% CI Lower	95% CI Upper
Kentucky River	256,977	64	249.1	249.3	191.9	318.3
Cumberland Valley	590,636	144	243.8	243.1	205.0	286.3
Buffalo Trace	143,312	33	230.3	231.2	159.1	324.6
Big Sandy	347,750	77	221.4	221.4	174.7	276.7
Northern Kentucky	1,229,624	269	218.8	218.9	193.6	246.7
Lincoln Trail	729,585	156	213.8	214.7	182.3	251.2
Purchase	472,148	95	201.2	200.8	162.4	245.5
Kipda	2,498,728	491	196.5	196.4	179.4	214.6
Lake Cumberland	512,685	100	195.1	194.5	158.3	236.6
Bluegrass	2,045,703	400	195.5	193.4	174.9	213.4
Green River	563,057	108	191.8	191.7	157.2	231.4
Pennyrile	566,047	107	189.0	186.8	153.0	225.9
Barren River	786,720	146	185.6	185.0	156.2	217.6
Fivco	321,114	59	183.7	184.4	140.4	237.8
Gateway	212,024	34	160.4	161.1	111.4	225.3
Kentucky	**11,276,110**	**2,283**	**202.5**	**201.8**	**193.6**	**210.3**

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2011-2020

AGE-ADJUSTED RATES BY AREA DEVELOPMENT DISTRICT

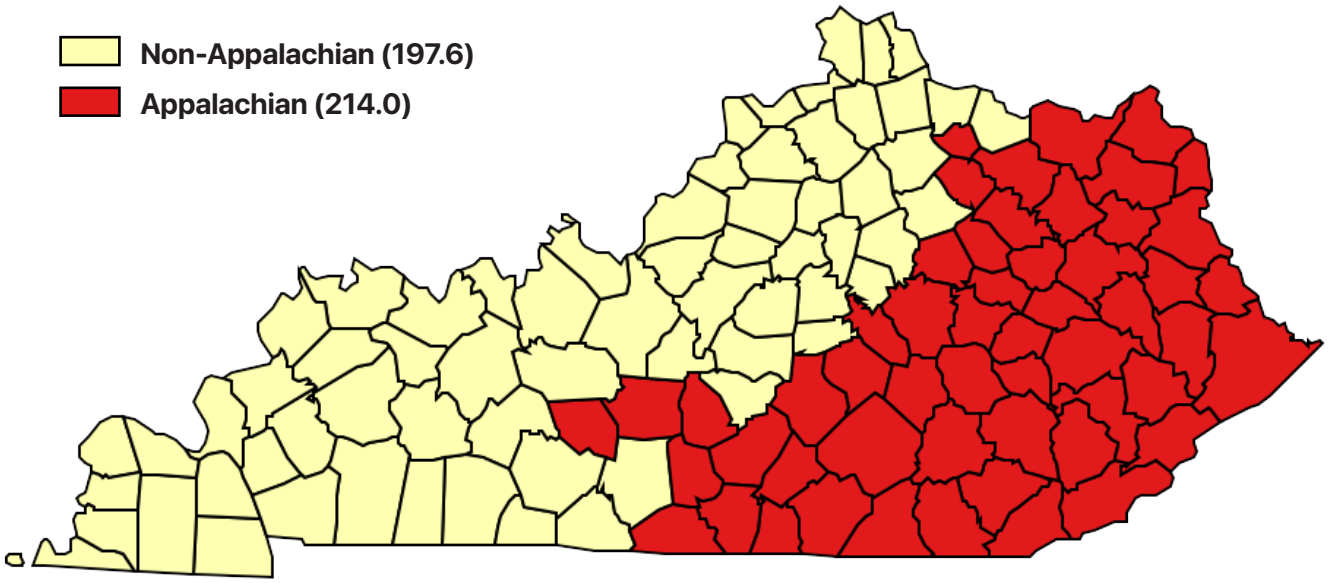




Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE IN KENTUCKY
ALL SITES, 2011-2020

AGE-ADJUSTED RATES BY APPALACHIAN REGION

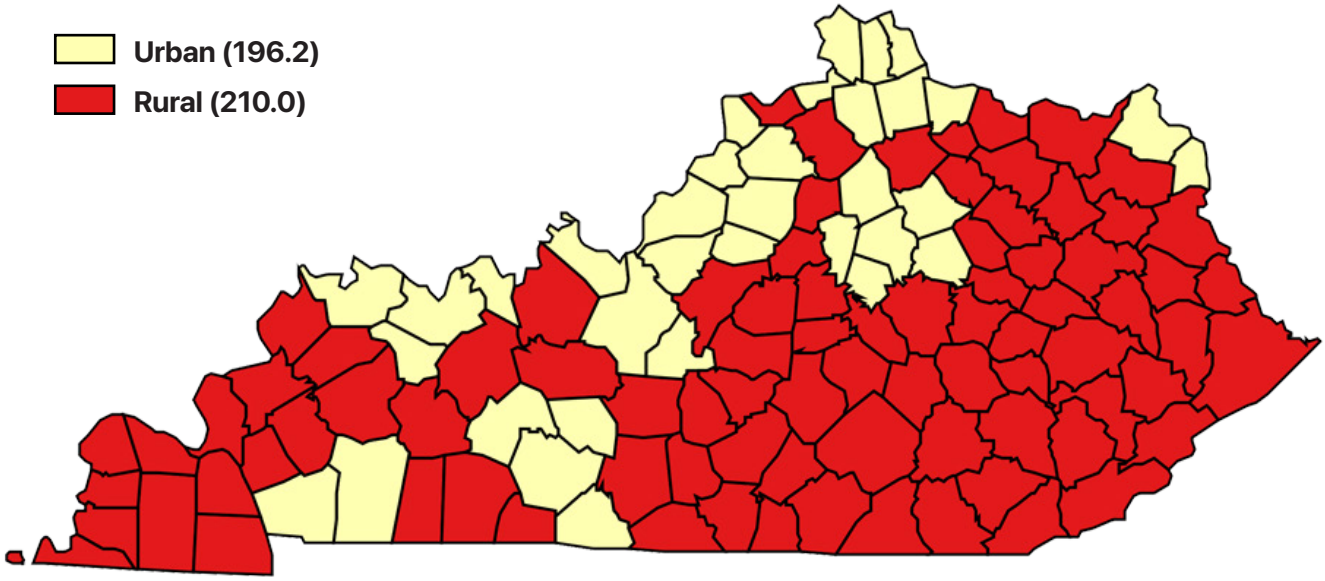


Region	Population at Risk	Cases	Crude Rate	Age-Adjusted Rate	95% CI Lower	95% CI Upper
Appalachia	2,893,415	622	215.0	214.0	197.5	231.5
Non-Appalachia	8,382,695	1,661	198.2	197.6	188.2	207.3
Kentucky	**11,276,110**	**2,283**	**202.5**	**201.8**	**193.6**	**210.3**

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE IN KENTUCKY
ALL SITES, 2011-2020

AGE-ADJUSTED RATES BY URBAN/RURAL REGION

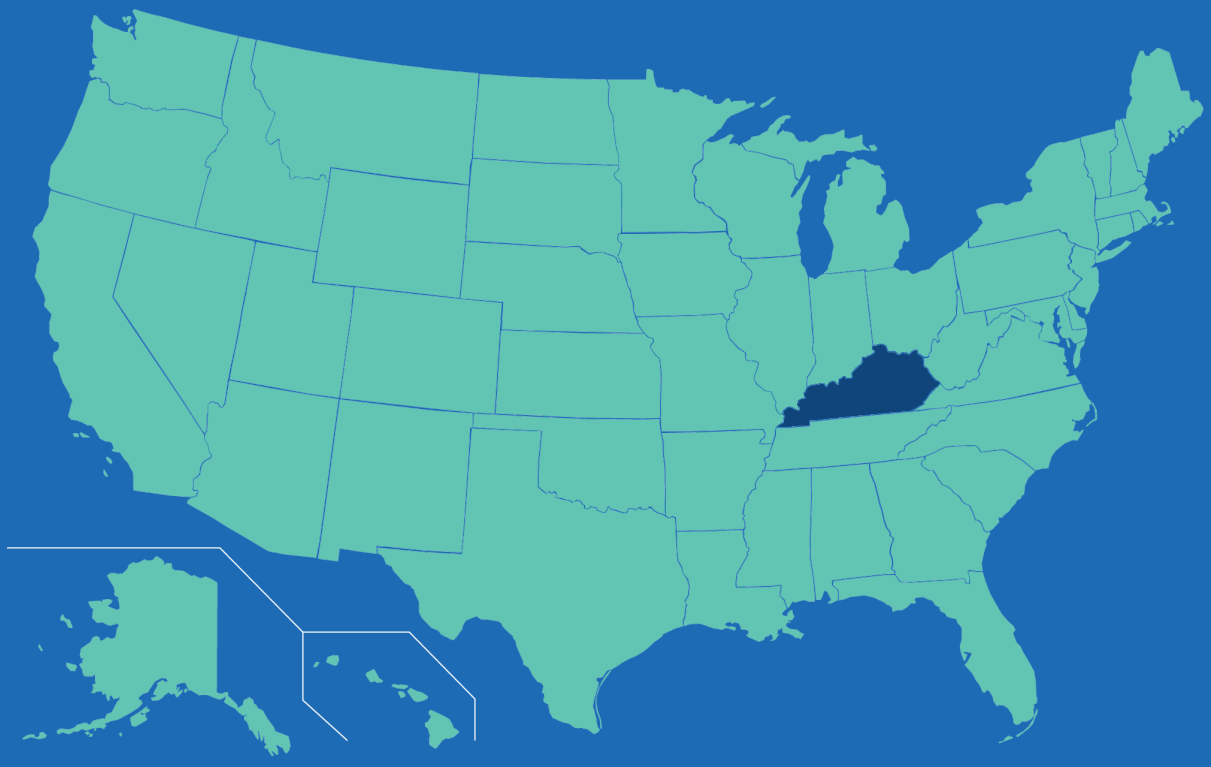


Region	Population at Risk	Cases	Crude Rate	Age-Adjusted Rate	95% CI Lower	95% CI Upper
Rural	4,567,057	962	210.6	210.0	196.9	223.7
Urban	6,709,053	1,321	196.9	196.2	185.8	207.1
Kentucky	**11,276,110**	**2,283**	**202.5**	**201.8**	**193.6**	**210.3**

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

Childhood Cancer Incidence Rates in Kentucky Compared to U.S.

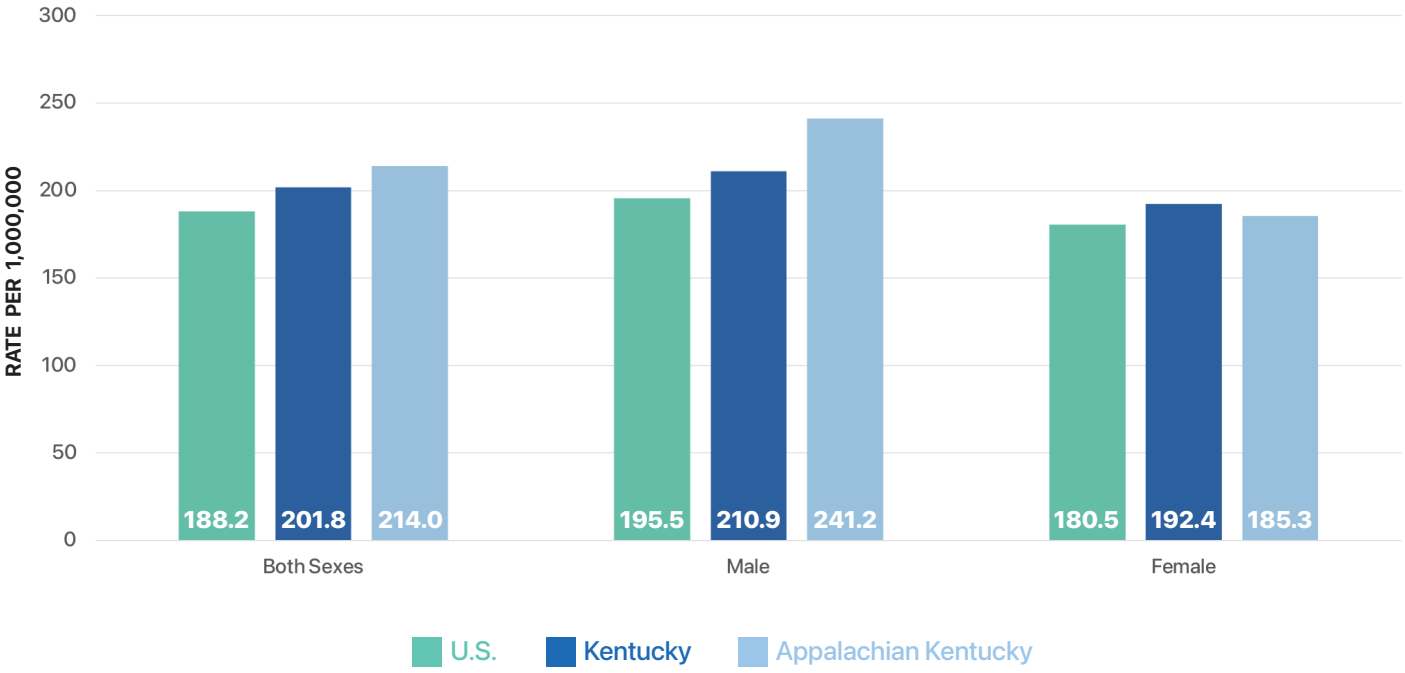
2011-2020



All U.S. rates and rankings were extracted from the CDC Wonder Cancer Statistics - https://wonder.cdc.gov/cancer.html

AGE-ADJUSTED CHILDHOOD CANCER INCIDENCE RATES ALL SITES, 2011-2020

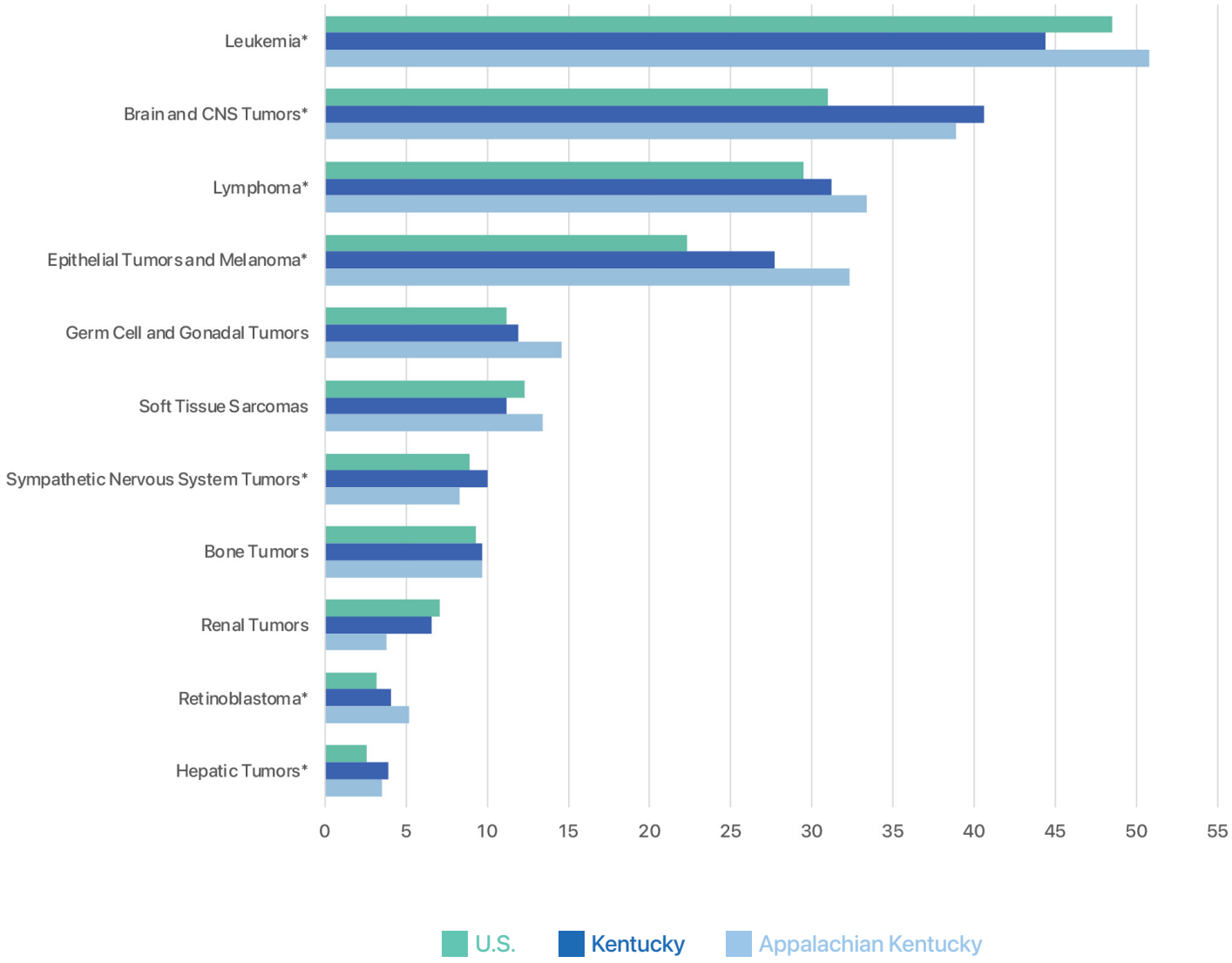
KENTUCKY COMPARED TO U.S. BY SEX



Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

AGE-ADJUSTED CHILDHOOD CANCER INCIDENCE RATES BY SITE GROUP, 2011-2020

KENTUCKY COMPARED TO U.S. BY SITE GROUP



***Rates are significantly different:**
Leukemia P < 0.05 (Kentucky rate compared to the U.S. rate)
Brain and CNS Tumors P < 0.01 (Kentucky rate compared to the U.S. rate)
Brain and CNS Tumors P < 0.05 (Appalachian Kentucky rate compared to the U.S. rate)
Lymphoma P < 0.05 (Kentucky rate compared to the U.S. rate)
Epithelial Tumors and Melanoma P < 0.01 (Kentucky and Appalachian Kentucky rates compared to the U.S. rate)
Sympathetic Nervous System Tumors P < 0.05 (Kentucky rate compared to the U.S. rate)
Retinoblastoma P < 0.05 (Kentucky rate compared to the U.S. rate)
Hepatic Tumors P < 0.05 (Kentucky rate compared to the U.S. rate)

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

AGE-ADJUSTED CHILDHOOD CANCER INCIDENCE RATES BY SITE GROUP, 2011-2020

KENTUCKY RANKINGS COMPARED TO ALL U.S. STATES

Site Group	Highest Ranking
Leukemia	32nd
Brain and CNS Tumors	4th
Lymphoma	20th
Epithelial Tumors and Melanoma	5th
Germ Cell and Gonadal Tumors*	14th
Soft Tissue Sarcomas	34th
Sympathetic Nervous System Tumors*	13th
Bone Tumors*	18th
Renal Tumors*	36th
Retinoblastoma*	3rd
Hepatic Tumors*	2nd
All Sites	**4th**

***One or more states outside of KY not available for comparison due to unstable rates.**

Supplemental Information

Definitions

Age-Adjusted Rate	A statistical adjustment applied to crude rates to permit comparisons of populations with different age structures. The 2000 Standard U.S. Million Population is commonly used in age-adjusted rates for cancer research in U.S. For childhood age-adjusted cancer rates, only the population for age groups 0 - 19 from the 2000 Standard U.S. Million population is used.
Annual Percent Change (APC)	Change in annual rates over time. The APC in this report was calculated through a log-transformation of the age-adjusted rates using the Joinpoint Trend Analysis software. https://surveillance.cancer.gov/joinpoint/
Appalachian Region	Groups of counties designated by the Appalachian Regional Commission's authorizing legislation. The region follows the spine of the Appalachian Mountains from southern New York to northern Mississippi. The current Kentucky Appalachian region includes 54 Kentucky counties https://www.arc.gov/appalachian_region/TheAppalachianRegion.asp
Area Development Districts	Groups of contiguous counties in Kentucky, comprising 15 area development districts. https://www.kyatlas.com/kentucky-adds.html
Cases	Total number of new incident cancer cases diagnosed in a given year or time period.
Childhood Cancer	A malignant cancer diagnosed in an individual under the age of 20.
Children's Oncology Group (COG)	A large group of researchers, hospitals, and cancer centers that get support from the National Cancer Institute (NCI) to study childhood cancer. https://www.childrensoncologygroup.org/index.php/aboutus
Crude Rate	An unadjusted incidence rate, calculated as the number of newly diagnosed cases divided by the population at risk.
Diagnosis Year	Year in which a cancer is first diagnosed.
Incidence Rate	Rate of new cancer diagnoses in a given year or time period.
P-value	The P-value, or calculated probability under the null hypothesis is used to quantify the idea of statistical significance of evidence. $P < 0.05$ is a convention generally accepted as representing a statistically significant finding.
Population at Risk	Number of individuals living in a geographical region and at risk of being diagnosed with cancer for a given year or time period.
Site Group	Type of cancer, grouped by topography and histology, as defined by the International Classification of Childhood Cancer. [1]
US Standard Million Population	The age distribution of individuals living in the U.S. in a given year, per million residents, as defined by the U.S. Census.
95% Confidence Interval (CI)	Specifies the precision of the age-adjusted rate measurement, resulting in a 95% certainty that the confidence interval includes the true value of the measurement.

1. Steliarova-Foucher E, Stiller C, Lacour B and Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer 103:1457-67, 2005.

Staff of the Kentucky Cancer Registry

Director	Eric B. Durbin, DrPH, MS
Associate Director	Thomas C. Tucker, PhD, MPH
Director of Population-based Studies	Bin Huang, DrPH, MS
Associate Director of Informatics	Isaac Hands, MPH
Information Technology Manager	Scott Grimes, PhD
Business Operations Manager	Jill Cioci, BBA
Epidemiologist/Research Coordinator	Jaclyn K. McDowell, DrPH, MPH
Virtual Tissue Repository	Kelly Pictor, BHS, CTR Lindsey Baker, BS, CTR
Quality Assurance Managers	Michele Hoskins, BA, CTR Shelly Gray, BA, CTR Desiree Montgomery, MPH, CTR
Senior Regional Coordinators	Wendy Drechsel, RHIT, CTR Marynell Jenkins, CTR Tracy Sumler, BA, CTR
Regional Abstractors	Leslie Benningfield, RHIT, CTR Amy Brewster, BS
Non-Hospital Abstractors	Stephanie Carmack, MS, CTR Danielle Darsey, RTT, CTR Sherry Gabehart, BS, RHIA, CTR Kim Kimbler, MS, CTR, CCRP Shannon Ladd, MSW, CTR Robin Walls
Quality Assurance Specialists	Jennifer Denham, RHIT, CTR Vicki LaRue, BS, CTR Paige Haydon Lutz, BS, CTR Mary Jo Mahoney, RHIT, CTR
Patient Recruitment Professionals	Stephanie Barber
Software and Database Developers	Chaney Blu Clay Campbell Roger Chui Jason Jacob, MS Luan Pham, MS David Rust, MS Evan Yang
Information Technology Support	Branson Repass Aaron Sword
Budget Analysts	Sarah Dickerson, BS, MPA
Administrative Assistants	Paula Cole Ivelina Todorova
Senior Biostatistician	Quan Chen, DrPH

Additional Resources

American Cancer Society
https://www.cancer.org/cancer/cancer-in-children.html

American Childhood Cancer Organization
https://www.acco.org/types-of-childhood-cancer

Childhood Cancer Data Initiative
https://www.cancer.gov/research/areas/childhood/childhood-cancer-data-initiative

Children's Hospital of Philadelphia
https://www.chop.edu/centers-programs/cancer-center

Children's Oncology Group
https://www.childrensoncologygroup.org

Cincinnati Children's Hospital
https://www.cincinnatichildrens.org/service/c/cancer-blood/cancer

DanceBlue
http://www.danceblue.org

Jarrett's Joy Cart
http://thejoycart.com

Kids Cancer Alliance
https://kidscanceralliance.org

Kentucky Children's Hospital – Pediatric Hematology & Oncology
https://ukhealthcare.uky.edu/kentucky-childrens-hospital/services/hematology-oncology

Kentucky Pediatric Cancer Research Trust Fund
https://chfs.ky.gov/agencies/dph/dpqi/cdpb/Pages/pcrtf.aspx

National Cancer Institute Center for Cancer Research Pediatric Oncology Branch
https://ccr.cancer.gov/Pediatric-Oncology-Branch

National Childhood Cancer Registry
https://cancercontrol.cancer.gov/research-emphasis/childhood-cancer-registry

NIH Kids First Data Resource Center
https://kidsfirstdrc.org

Norton Children's Cancer Institute
https://nortonchildrens.com/services/cancer

raiseRED
https://raisered.org

Tracking Pediatric and Young Adult Cancer Cases
https://www.cdc.gov/cancer/npcr/pediatric-young-adult-cancer.htm

Vanderbilt University Medical Center Pediatric Cancer Program
https://www.childrenshospitalvanderbilt.org/service-line/pediatric-cancer-program

Why Not Kids?
http://whynotkids.com